



Curatorial Text

KINGDOM OF THE ILL:

Emergent Discourses on Access in the Arts

By Sara Cluggish and Pavel S. Pys´

The last few years since the beginning of the covid-19 pandemic have brought all matters of health and illness into sharp relief. The novel coronavirus outbreak has not only informed debates on the national, financial, political, and ideological dimensions of healthcare provision, but shaped our very personal experiences of how we receive and provide care, guard personal space through social distancing, and make decisions on whether or not to participate in sharing physical space with others. For those who identify as ill or disabled, this physical isolation and hyperawareness of one's body is typically the norm, not the exception. Reflecting on this shift in public consciousness, writer and artist Johanna Hedva facetiously remarked: "It's funny to me that in 2020, we're all behaving as if illness is this completely foreign, brand new experience (...) we instead kind of push it out into this, this exile, this banishment (...) and I just think all of that is bullshit. Everyone gets sick. This is just a part of being alive". [1] Sickness is not a singular state of being or moment in time but a continuum. The title of our exhibition — *Kingdom of the Ill* —invokes American writer and political activist Susan Sontag's work of critical theory *Illness as Metaphor* (1978), specifically Sontag's suggestion that we each hold dual citizenship: one to the kingdom of the well, and another to the kingdom of the sick, and that we must at one point or another identify with either. The idea that any one of us can ever truly reach the idealized "healthy" state of productivity that capitalism promotes is a fallacy. In striking out the binary separating these two "kingdoms," we resist Sontag's demarcation, instead drawing attention to the ways that wellness has become an impossible goal under advanced capitalism. [2] In the words of economists Raj Patel and Jason W. Moore: "To ask for capitalism to pay for care is to call for an end to capitalism." [3]

Kingdom of the Ill was spurred by the observation that over the past decade, artists have increasingly embraced their own diagnoses, bringing their lived experience into public view and demanding we openly and transparently give over space for discourse surrounding health and illness. Following their lead, many arts organizations have gradually shifted toward embracing programming on themes of sickness and wellness [4], exploring how we define normative understandings of what constitutes a "healthy" body. Exhibitions and public programs have asked questions such as: What are our roles as consumers of both traditional pharmaceuticals and natural therapies? How might environmental devastation and pollution affect our



health? What advances in technology and speculative fiction have shifted the landscape of illness and wellness?

In her 2018 performative lecture *The Art of Dying or (Palliative Art Making in the Age of Anxiety)*, filmmaker Barbara Hammer spoke to this change against the backdrop of her own experience of living with advanced cancer: “all of us—artists, curators, administrators, art lovers alike—are avoiding one of the most potent subjects we can address. I’m happy to see there is a recent change in a few organizations that are planning seminars on health, illness, death, and dying right now, and artists are coming out with transparency finally as they break the fear of coming out as ill.” [5] While the topic has gained visibility, it has simultaneously become painfully evident that arts organizations lack the infrastructure or financial means to support the working modes of artists who identify as chronically ill or crip [6], much as they may want to embrace the artwork they make. The onus has often fallen to artists themselves, and as a consequence, many have been sharing their personal *access riders* online. [7] These customizable documents outline one’s disability needs with the aim of creating “access intimacy”: a term defined by justice activist Mia Mingus as “... that elusive, hard to describe feeling when someone else ‘gets’ your access needs.” [8] Provided at the beginning of a working relationship, access riders can help artists to define and protect parameters of fair pay, project timelines, personal care assistants, childcare, food and dietary restrictions, travel and lodging requirements, mobility needs, and the accessibility of the venue or event taking place. Importantly, they also allow artists to define how and to whom their disability or illness is disclosed and protect artists from having to taxingly communicate and recommunicate their access needs. Through this practice, the onus shifts from artist to institution, whereby the museum is challenged to reflect on entrenched working practices and adapt to new procedures. As is often the case, artists take it upon themselves to advance this work before institutions: in 2019, artist and writer Carolyn Lazard published *Accessibility in the Arts: A Promise and a Practice*. This freely available toolkit sets out pathways for smallscale arts nonprofits to facilitate and support relationships with artists, addressing barriers and opportunities. Within this guide, Lazard succinctly gets to the crux of the issue in addressing the artistdriven rapidly advancing discourse and the slow pace of institutions: “There is often a striking discord between an institution’s desire to represent marginalized communities and a total disinvestment from the actual survival of those communities.” [9]

Park McArthur’s *Carried & Held* (2012) is a deceptively simple artwork: a list that in format approximates a museum label, identifying every person who has lifted McArthur, who uses a wheelchair as she suffers from a degenerative neuromuscular disease. Friendship, community, networks of care, mutual aid: these collective efforts are at the very heart of what has energized the shift in discourse around illness, ableism, and inclusivity. The exhibitions, public programs, publications, and workshops of artist collectives—including Canaries, Feminist Healthcare Research Group, Pirate Care, Power Makes Us Sick, and Sickness Affinity Group, among



others—have elevated concerns with denial of access relative to illness and disability, demonstrating how these are negotiated at the intersection of not only ability but also race, gender, sexuality, and class. Galvanized by historical precedents—especially groups such as ACT UP, the Art Workers’ Coalition, and more recently, w.a.g.e. and Decolonize This Space—the work of many of the artists and collectives cited here dovetails with activism, with a real call for increased transparency, equity, support infrastructures, as well as systemic change, both within and beyond the artworld. Through flexible membership models that can function as part support group, part activist networks, and (in some cases) part art collective, many groups have centered their focus on publicfacing protests and boycotts, as well as mutual aid fundraising. Since 2017, artist Shannon Finnegan has produced two versions of their interactive installation *Anti-Stairs Club Lounge* that responds to the inaccessibility of architectural sites: the Wassaic Project Space in Maxon Mills (2017–18) and the Thomas Heatherwick designed “Vessel” in New York. In the case of the latter, together with a range of disabled and nondisabled participants, Finnegan protested the structure, calling for a permanent “AntiStairs Club Lounge” with a budget of \$150 million (equivalent to the entire structure budget). These sites hold inherently ableist assumptions, just as modes of engaging with exhibitions and accessing museum spaces do, and artists such as Finnegan are thus crucial voices in demonstrating how these spaces must change for equitable access. In 2020, several disabled, chronically ill, and immunocompromised people rallied together to create the CRIP Fund, with the specific aim of redistributing donated funds to those same communities affected by the covid19 pandemic. Mutual aid endeavors such as the CRIP Fund (as well as the work of the collective Sick in Quarters) make painfully evident the need for artists to turn to collective action in the face of the inadequacy of staterun healthcare systems and the boogeyman known as the medical industrial complex. In *The Hologram* (2020), which sets forth a vision for revolutionary care centered on viral, peertopeer feminist health networks, artist Cassie Thornton laments this very sense of entrapment: “We don’t see this as a choice because it seems impossible to sacrifice our access to our means of survival under financialized capitalism by reaching for an uncharted experience of collectivity, care, and mutual aid, abandoning the idea that we can become successful capitalist subjects.” [10]

These efforts advance parallel to large social movements—racial reckoning, rallying around student debt, the #MeToo movement, climate advocacy, ongoing calls for corporate accountability—that seek an undoing of continuing injustices and violence, many of which are seeded by the logic of capitalism that perpetuates profithungry greed, division, and indebtedness. With so many of these activities run at a grassroots level, a valid question surfaces: when will we see meaningful change? How are discourses on health and illness informing the broader social debate? For arts institutions: will the roving museal eye soon shift its short attention elsewhere? In February 2022, the announcement was made that Purdue



Pharma would dissolve and issue a \$6 billion payment to settle the lawsuits associated with the opioid crisis. The company, owned by the billionaire Sackler Family, is responsible for the production and aggressive marketing of OxyContin: a highly addictive opioid, prescribed to millions of patients suffering from minor ailments. Artist Nan Goldin and the activities of P.A.I.N. (Prescription Addiction Intervention Now) played a role in raising public awareness around Purdue Pharma's complicity in the opioid crisis, as well as the Sacklers' brazen efforts to harness their significant philanthropic support of arts institutions as a means to whitewash their reputation and money. [11] Between 2018 and 2019, Goldin and P.A.I.N. staged protests and "diein" demonstrations (in which participants would lie lifeless on the floor) at museums that had accepted funding from the Sacklers: the Guggenheim, Harvard Art Museums, Louvre Museum, Metropolitan Museum, Smithsonian, and Victoria & Albert Museum. Littering these spaces with faux OxyContin bottles, prescription slips, and banners bearing slogans such as "Shame on Sacklers", Goldin and P.A.I.N. elevated the matter within the broad social consciousness. While certainly a judicial victory, the ruling ultimately protected the Sacklers, who remain absolved of liability and continue to be one of the richest us families. As Goldin said of the ruling: "it's been a real lesson in the corruption of this country to watch this court, that billionaires have a different justice systems than the rest of us, and that they can actually walk away unscathed." [12]

The activities of P.A.I.N. are as much about the opioid crisis, as they are about the broader health and condition of artsfunding structures. The Sacklers are just one of the many donors, whose wealth has come under increased scrutiny over the last few years. Liberate Tate, an art collective that aims to "free art from oil" were successful in demanding that the museum sever ties with bp in 2017, while protests by Decolonize This Space contributed to Warren Kanders—whose company Safariland produces teargas grenades that have been used against migrants at the us –Mexico border—resigning from the Whitney board in 2019. The swell in reckonings with toxic philanthropy is symptomatic of our present moment: the health of our museums, and by extension our larger institutions, is contingent on how we remediate the ills of capitalism and instead embrace equity, fairness, and representation.

"Follow the money," as the saying goes, and it's unsurprising that the most expressibly visible changes are taking place at the level of funding. Yet, there is so much more work to be done, far beyond merely ensuring representation of those who identify as ill or disabled. While the covid19 pandemic has urged us to rethink the stark boundaries between the "healthy" and the "ill" as blurred, nuanced, or simply untrue, we might realize that necessary change runs much deeper. All forms of bodies—arts institutions and beyond—are seldom agile or nimble, yet change is needed that gets right to the heart of how they are funded, who staffs them, and the accessibility practices they design for the communities they serve.



Beyond even this, we must learn new vocabularies, ways of communicating, of caring for one another—only then might we inch closer towards the feeling, as Mia Mingus put it, of “getting” one another’s access needs.

[1] Nwando Ebizie, host. “The Mediated Body.” *For All I Care*, season 1, episode 1, BALTIC Center for Contemporary Art, <https://baltic.art/whats-on/podcasts/for-all-i-care>.

[2] To clarify, we are in no way suggesting a collapse of the distinction between those who identify as able-bodied or disabled. We are instead refusing the hard distinction proposed by Sontag and her characterization of illness as the “night side of life” or the “more onerous citizenship.” We refute the possibility of separating health and illness, and refuse the symbolic connotations of the characterizations she employs to describe illness (See Sontag, Susan. *Illness As Metaphor*, Vintage Books, New York, 1979, p. 3).

[3] Jason W. Moore & Raj Patel. *A History of the World in Seven Cheap Things: A Guide to Capitalism, Nature, and the Future of the Planet*, University of California Press, 2018, p. 113.

[4] A selection includes: *Sick Time, Sleepy Time, Crip Time: Against Capitalism’s Temporal Bullying*, efa Project Space New York (2017), toured to Bemis Center for Contemporary Arts (2018), Red Bull Arts Detroit (2019); *I wanna be with you everywhere*, Performance Space New York (2019); *When the sick rule the world*, Gebert Foundation, Rapperswil (2020); *CRIP TIME*, Museum Für Moderne Kunst Frankfurt (2021); *Take Care: Art and Medicine*, Kunsthau Zürich (2022).

[5] Barbara Hammer. *The Art of Dying or (Palliative Art Making in the Age of Anxiety)*, The Whitney Museum of American Art, October 10, 2018, <https://whitney.org/media/39543>.

[6] Lauryn Youden defines “crip” in the exhibition booklet for her 2020 solo exhibition *Visionary of Knives* at Künstlerhaus Bethanien, Berlin as follows: “Crip is a term many people within disability studies and activist communities use not only in reference to people with disabilities, but also to the intellectual and art culture arising from such communities. Crip is shorthand for the word ‘cripple’ which has been (and is) used as an insult toward people with disabilities, but which has been re-appropriated as an intra-group term of empowerment and solidarity.” An early proponent of crip’s social and political potential, Carrie Sandahl (2003) describes crip as a fluid and ever-changing “...term which expanded to include not only those with physical impairments but those with sensory or mental impairments as well.” (See Alison Kafer, *Feminist Queer Crip*, Indiana University Press, 2013).

[7] Johanna Hedva. “Hedva’s Disability Access Rider” Tumblr Blog, August 22, 2019, <https://sickwomantheory.tumblr.com/post/187188672521/hedvas-disability-access-rider>; Leah Clements, Alice Hattrick & Lizzy Rose. Access Docs for Artists website, March 26, 2019. <https://www.accessdocforartists.com/>.

[8] Mia Mingus. “Access Intimacy: The Missing Link,” *Leaving Evidence*, May 5, 2011. <https://leavingevidence.wordpress.com/2011/05/05/access-intimacy-the-missing-link/>

[9] Carolyn Lazard. “Accessibility in the Arts: a Promise and a Practice,” *Common Field and Recess*, April 25, 2019. <https://www.commonfield.org/projects/2879/accessibility-in-the-arts-a-promise-and-a-practice>.

[10] Cassie Thornton, *The Hologram: Feminist, Peer-to-Peer Health for a Post-Pandemic Future* (2020), Pluto Press, available online: <https://vagabonds.xyz/the-hologram/>

[11] Taylor Dafoe. “They Are Going to Stand by Us: Text Messages Between Members of the Sackler Family Show How They Leveraged Their Museum Philanthropy Into Positive pr.” *Artnet News*, 20 December 2022, <https://news.artnet.com/art-world/sackler-family-text-messages-museums-1933901>.

[12] Nan Goldin quoted by Jones, Sara. “It’s a Real Lesson in the Corruption of This Country. Anti-Sackler activist Nan Goldin on the Purdue Pharma bankruptcy settlement.”, September 1, 2021. <https://nymag.com/intelligencer/2021/09/nan-goldin-onpurdue-pharma-sackler-settlement.html>